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AHA SCIENTIFIC STATEMENT

Palliative and End-of-Life Care in Stroke: A Scientific Statement From the American Heart Association

The American Academy of Neurology affirms the value of this statement as an educational tool for neurologists.

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OBJECTIVE: To provide an update on palliative care needs specific to stroke and provide key points for clinicians and health care systems caring for patients with stroke and their families.

METHODS: Members of the writing group were chosen to represent the multidisciplinary team of professionals who care for people who have had a stroke. Each member was assigned a topic within their area of expertise, reviewed the literature, and drafted content with a focus on the past decade to complement the 2014 American Heart Association scientific statement on palliative and end-of-life care in stroke.

RESULTS: Stroke has multidimensional effects on patients and their families because of threats to personhood, prognostic uncertainty, and the need to adapt to functional changes after stroke. Palliative care has evolved as both a specialty and a skillset with a goal to improve communication about goals of care and quality of life for patients and their families that emphasizes a holistic, all-person approach. After stroke, palliative care needs (eg, to address pain and physical, emotional, psychosocial, and spiritual distress) are insufficiently addressed by current models of care. Integrating palliative care principles is fundamental in all stages of stroke and should include strategies to improve communication about prognosis and goals of care, address psychosocial needs such as coping with loss, navigating complex health care systems, and preparing for death when necessary. We also review strategies to address the substantial inequities that exist across sociodemographic and regional strata in the use of life-sustaining treatment and access to specialists in stroke or palliative care.

CONCLUSIONS: Palliative care needs are common after stroke and should be addressed throughout the illness continuum. Research is urgently needed.

Key Words: AHA Scientific Statements ■ palliative care ■ stroke ■ terminal care

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Stroke is common, disabling, and often deadly. Every year, 800 000 people experience a stroke in the United States, and 140 000 people die as a result. Recent advances in acute stroke treatment have led to reduced morbidity and mortality rates, but also to an increased number of survivors, who, along with their family members, are faced with long-term challenges, ranging from cognitive and physical disabilities to psychosocial and existential distress. Palliative care focuses on improving communication about goals of care and quality of life for both patients and their families, emphasizing a holistic, all-person approach. Palliative care also encompasses hospice and end-of-life care, with aims to improve the quality of care for people who are dying and their families.

Neuropalliative care has emerged from an understanding that the palliative care needs of patients with neurologic diseases are unique.[1,2] Whereas the majority of strokes are not immediately life-threatening, they are always life-altering, and always require high-quality, person-centered care.

Integrating palliative care principles into stroke care is fundamental in all stages of stroke. High-quality

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stroke care should always include primary palliative care, which is palliative care provided by the primary medical team who is trained in communication skills and are able to assess and manage patient and family needs effectively, either themselves or through referral to other specialists. Given that a holistic approach to stroke care is required at varying time points from the initial hospitalization through months and years of recovery for some patients, stroke health care professionals and primary care physicians should be trained in primary palliative care and skilled in the early assessment and management of palliative care needs. A palliative care specialist team, if available, may be needed in cases with more complex symptoms, situations, or communication needs.[3]

The first American Heart Association (AHA) scientific statement on palliative and end-of-life care in stroke[4] covered core palliative care competencies and skills for the stroke health care professionals and emphasized the need for further research in this area. Since then, substantial growth has occurred in various areas related to stroke and palliative care, including neuropalliative care,[5,6] neurorehabilitation,[7] understanding of covert consciousness,[8] and an increasing recognition of the importance of care partner support[9,10] and postacute stroke care.[11]

Our goal for this 2024 scientific statement is to provide an updated summary with an emphasis on developments over the past decade, focusing on the adult patient with stroke. We discuss health care disparities specific to stroke and palliative care, how to assess for and manage distressing symptoms and other palliative care needs among patients and their family care partners, challenges of postacute care after stroke survival, and end-of-life care. The term "family" in this article is not limited to those who are related to the patient by blood or marriage, but includes people who are closely involved with the patient.

Wide variability in prognostication, communication, assessment, and management of complex needs among both patients and families exists. This scientific statement emphasizes the palliative care approach to stroke care, which is a holistic approach to address the multidimensional needs of patients facing stroke (in particular, severe stroke) and their family members that embraces a biopsychosocial model of care.[12]

RACIAL OR ETHNIC HEALTH CARE INEQUITIES

Inequities in health care treatment and outcomes across race and ethnicity are pervasive throughout medicine. Whereas health care disparities exist across many domains (eg, sex, gender, geographic region), this section focuses on disparities related to race or ethnicity, predominantly in the US context, acknowledging that other issues related to treatment inequalities also must be addressed. A recent AHA scientific statement[13] outlines the underlying context for longstanding racial and ethnic inequities in stroke, and points out that social determinants of health are largely responsible for these historical differences, including systemic and structural racism, as well as unequal distribution of wealth. Disparities in stroke incidence, outcomes, and acute stroke treatment have been demonstrated repeatedly, with Black and Hispanic populations generally shown to have a higher stroke incidence, worse functional outcomes, and less frequent receipt of acute stroke treatments such as intravenous thrombolytic or mechanical thrombectomy.[14]

Inequities by race or ethnicity also have been found in advance care planning and patterns of serious illness treatment after stroke. In general populations, Black or Hispanic individuals are consistently less likely to have advance directives compared with White individuals; for example, 1 nationally representative study demonstrated that Black individuals had 77% and Hispanic individuals had 70% lower odds of completing an advance directive compared with White individuals.[15] People from historically underrepresented racial or ethnic groups are also less likely than White individuals to have do-not-resuscitate orders or transition to comfort measures only,[16,17] and are more likely to use long-term life-sustaining treatments, such as tracheostomy or percutaneous gastrostomy tube.[18] A study of severe acute brain injury that included stroke also demonstrated less frequent discharges to hospice of Black, Hispanic, or Asian individuals when compared with White individuals.[19]

Whereas these treatment patterns may partially reflect underlying individual or cultural differences in preferences for treatment, assuming that these observed care patterns are solely attributable to patient factors ignores the long history of inequities in care resulting from upstream factors, such as structural racism and implicit bias, and does not account for the role of clinicians and the health care system.[20] For example, a major driver of "palliative care use" (in this case, use of a comfort care pathway) is the hospital at which the patient received treatment, independent of race or ethnicity, suggesting that systems-level factors contribute to these inequities.[21] Hospital-level do-not-resuscitate orders have also been shown to affect inpatient mortality rates.[22] More work is needed to better understand the role of clinicians, hospitals, systems, and upstream factors in these long-observed differences in serious illness care patterns to ensure that treatments appropriately support patient and family needs while striving to eliminate effects of bias and racism.[13]

Systematic tailored interventions may help mitigate these historical inequities. For example, a recent implementation trial of a goals-of-care conversation priming guide in older hospitalized patients with chronic illnesses showed that use of this guide improved documentation

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of goals-of-care conversations, with a greater effect size in patients from historically underrepresented racial or ethnic groups.[23] In a randomized trial of Hispanic patients with noncancer serious illness, a bilingual, bicultural lay patient navigator did not improve quality of life, but substantially increased engagement in advance care planning and hospice use.[24] Ongoing work studying the effects of a community-developed culturally based palliative care teleconsultation program designed for rural southern Black and White populations could be adapted for stroke care.[25] The recent scientific statement from the AHA, titled "Strategies to Reduce Racial and Ethnic Inequities in Stroke Preparedness, Care, Recovery, and Risk Factor Control,"[13] outlines strategies that may be undertaken to help mitigate these inequities at various stages of disease, notably the need to address upstream factors, such as structural racism and interventions that consider social determinants of health (eg, housing and food security, economic security), and to undertake approaches that are multifaceted and comprehensive. These efforts to reduce historical inequities should continue, including culturally tailored interventions focused on the needs of diverse communities of patients with severe stroke and their families.

PALLIATIVE CARE NEEDS AND HOLISTIC ASSESSMENT

Patient- and family-centered palliative care requires a comprehensive assessment of multidimensional distress that has been conceptualized as the "total pain of illness,"[26] and includes symptoms and needs that go beyond physical pain, including emotional, psychosocial, spiritual, and existential distress. At the center of this multidimensional assessment is a proactive and holistic exploration of the effects of the stroke on the patient and their family, their expectations after the stroke, their values, and their goals of care (Figure 1). The "total pain" concept illustrates the need for health care professionals to focus on sources of distress beyond the physical recovery of stroke, and to acknowledge the effects on patients and their family care partners. Sources of anxiety and the effects of illness and disability on quality of life and treatment decisions will vary across individuals on the basis of their values, beliefs, and culture, requiring an individualized and culturally sensitive approach to assessment and management.[27,28]

The palliative care needs of patients and their care partners fluctuate over the course of the illness on the basis of events, symptoms, changes in function, and stage of the illness. The trajectory of stroke is distinct from that of other serious illnesses[29]; the trajectory of needs is also distinct. Figure 2 shows 6 proposed stages after severe stroke, each of which requires a different focus of support.[30] Trajectories may vary among individuals with the same diagnosis, and clinicians need to assess multidimensional needs carefully and proactively.[31] Certain events that occur during the course of an illness can also serve as signposts indicating a change in health status or signaling prognostic implications. Examples of such events include a change in neurologic examination results or medical condition, rehospitalization, or the end of a time-limited trial. If anticipated, such events can prompt clinicians and patients to discuss changes in management, treatment, the status quo, goals of care, and the patient's and family's needs, hopes, and fears for the future. Such events may also trigger a referral to a specialty palliative care or hospice team. There is tremendous interest in defining appropriate screening tools or triggers to identify patients who may warrant reassessment of goals of care, referral to specialty palliative care, or referral to other services (eg, spiritual care). Table 1 lists examples of palliative care needs checklists or screening tools that may assist health care professionals in the timely recognition and management of needs. Research in this area is ongoing and more work is required to understand the optimal criteria and appropriate action when a trigger is met.

Pain and Other Physical Symptoms

Common physical symptoms are outlined in Table 2. Poststroke pain exhibits a trajectory, with highest severity of pain at 4 to 6 months and >2 years after stroke,[37] and continues to be underdiagnosed and poorly controlled, suggesting that clinicians need to ask about and assess for poststroke pain symptoms carefully. In patients who are unable to communicate, nonverbal indicators of discomfort, such as the Critical Care Pain Observation Tool, which has been used in adults with brain injury, may be valuable.[38,39]

Emotional Support

After a stroke, both patients and care partners experience various changes to their prestroke life, identity, and roles[41,42]; they often struggle to cope with this sudden major illness, and have reported feeling insufficiently prepared for the future.[41] High levels of anxiety and depression among surrogates of patients with acute severe brain injury, such as stroke, persist through the postacute period and need to be addressed.[43] Skilled communication from their stroke health care professionals needs to include a commitment to meaningful engagement and nonabandonment throughout the stroke trajectory.[44,45] Prognostic uncertainty can be a considerable source of distress after severe stroke, and families need guidance and support. Patients who have experienced stroke and their care partners should be viewed as a "unit of care."[46,47] Dyadic interventions (ie, those that intervene with both the care recipient and their support person

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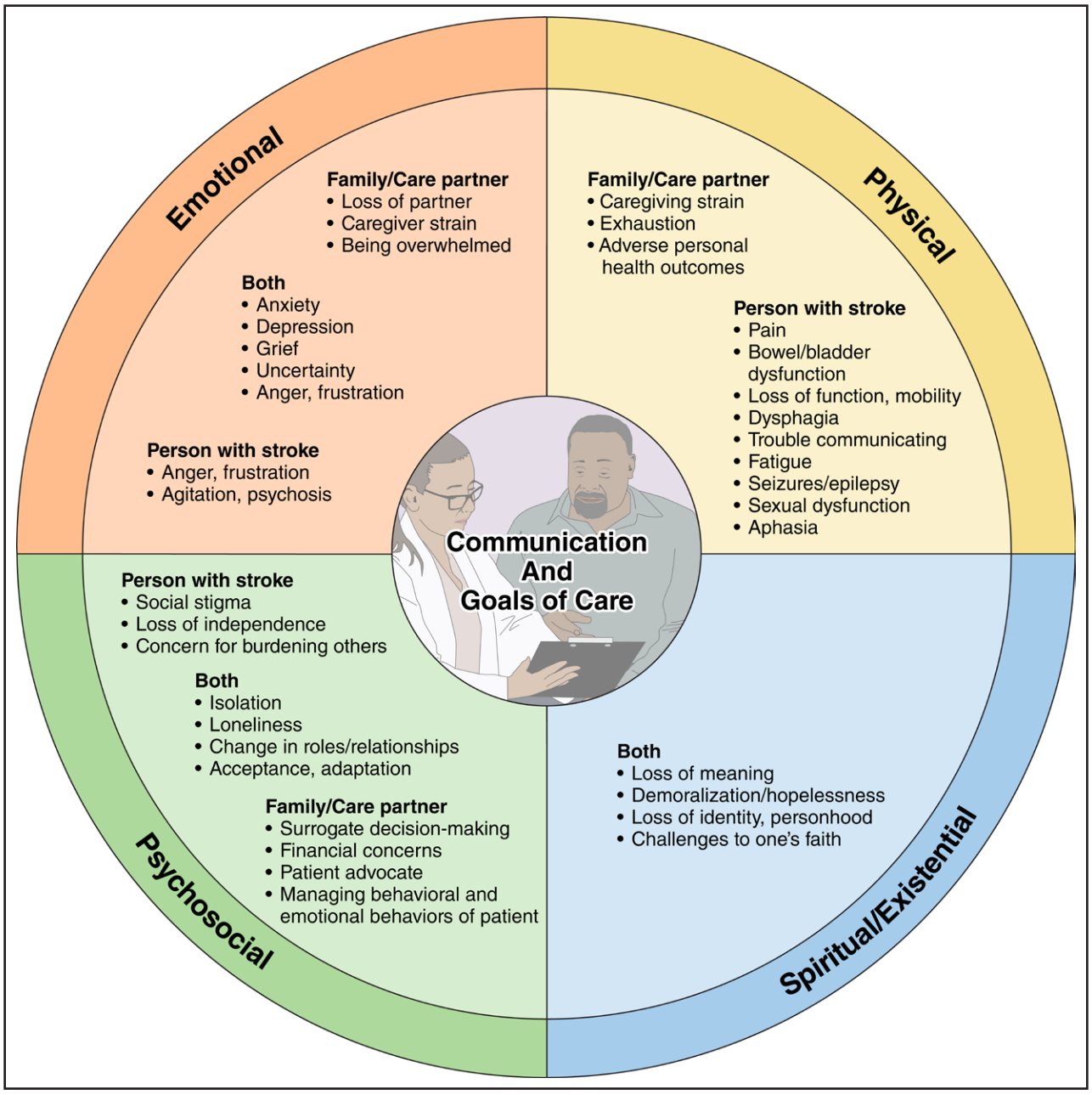

Figure 1. Total pain model for stroke.

together) may improve physical functioning, memory, and quality of life for the stroke survivor and depression symptoms for the care partner.[47,48]

Psychosocial Support

In the setting of acute severe stroke, family members must step into the role of surrogate decision-makers, and need to try to honor patient autonomy through substituted judgment as they face highly consequential treatment decisions while facing the possible loss of the person they knew.[49] Such tasks require multidimensional support from the clinician team, who should provide needed unbiased, prognostic information, offer treatment options, and provide emotional support.

Spiritual Support

Serious illness, including stroke, challenges spiritual well-being, whether people identify as religious or not. Spiritual distress—a disruption of a person's value or belief system—can lead to a loss of strength, hope, and sense of meaning.[50] In the face of prognostic uncertainty after acute severe brain injury, families describe the need to maintain hope.[49] However, health care professionals rarely address spiritual concerns, even when raised by

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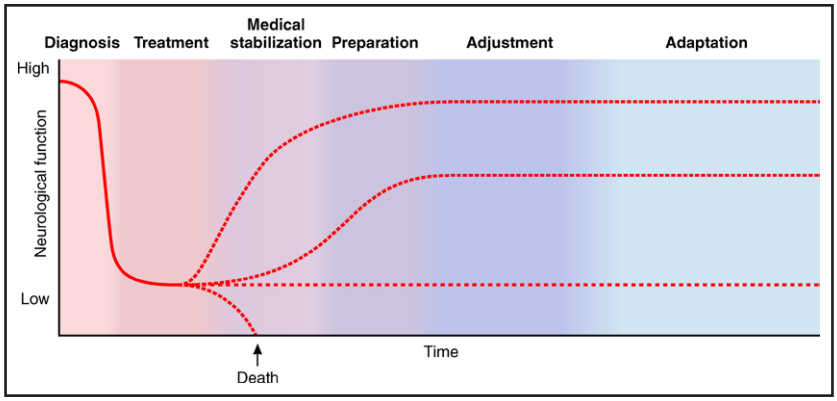

Figure 2. Phases after severe stroke.
Diagnosis is the time of presentation. Clinicians provide informational support to patients and families. **Treatment** after severe stroke typically necessitates shared decision-making concerning treatments such as intubation, mechanical ventilation, thrombectomy, brain surgery, artificial nutrition, and hydration. This is a stressful time, especially for families, and may lead to an early decision to withhold or withdraw life-sustaining treatment. The phase of **medical stabilization** is often when decisions for longer-term treatments are made, such as percutaneous endoscopic gastrostomy tube placement, tracheostomy, or comfort measures, in attempts to provide individual, goal-concordant care. Disposition is discussed with families. The **preparation** phase occurs before the patient returns home. After a severe stroke, this typically starts in an inpatient rehabilitation or nursing home setting. In the adjustment phase, the responsibility for providing care shifts from clinicians to family caregivers. Patients and families are learning (and need support with) how to navigate life in their home environment. **Adjustment** is mostly a practical process and includes care coordination and continuity of care. Outpatient rehabilitation programs may continue. **Adaptation** is an emotional process that should be supported early in the illness course but is particularly relevant when further neurologic recovery is limited. Data are derived from Cameron and Gignac.[30]

family members.[51] A recent observational study in medically hospitalized adults suggested that emotional and spiritual support from clinicians were associated with better long-term psychological outcomes for surrogate decision-makers, whereas increased provision of information was not.[52] Randomized controlled trials have suggested improved outcomes among family members who received specialized spiritual care support in a general intensive care unit population[53] and among patients with mild stroke.[54] Clinicians should ask their patients and families about spiritual or religious beliefs and offer referral to a chaplain or spiritual care.[4]

Communication and Goals of Care

A primary aim of palliative care is to provide goal-concordant care, which is care that is aligned with the individual goals of care of the patient.[55] This requires clinicians to (1) assess the patient's and family's understanding and perception of their current condition, values and preferences, and hopes and fears for the future, including potential trade-offs (ie, "What would you be willing, or unwilling, to endure for a certain outcome?"); (2) provide tailored and honest information about the illness, prognosis, and treatment options; and (3) consider a treatment recommendation that aligns with these.[56]

After stroke, prognostic uncertainty can lead to feelings of anxiety and spiritual distress and hinder early goal concordance. This uncertainty includes clinical uncertainty regarding the extent of functional and cognitive recovery and the affective uncertainty of how the patient and family may adapt emotionally to future disability.[57,58] Skilled communicators acknowledge the difficult emotions associated with not having a clear answer or path ahead and help patients and families adapt and cope with new possible futures.[59] Even when the eventual outcome is uncertain, clinicians can provide a road map describing anticipated next steps in management and in the clinical condition, and alleviate uncertainty by describing a best-case, worst-case scenario.[60] Prognosis discordance between family care partners and physicians is common in the setting of acute severe stroke and is typically caused by a combination of misunderstanding and belief differences, which in turn may be driven by faith, optimism, or uncertainty.[61] It is important to understand the perspective of patients and families to manage the discordance appropriately.

Prognostic uncertainty also affects decision-making, as it can be challenging to know whether a proposed treatment course is goal-concordant when outcomes are unclear. A time-limited trial can provide structure and support as families navigate life-or-death decisions. A time-limited trial is a way to provide more intensive care temporarily, for an agreed-on time period, to allow all parties to better understand the likely prognosis, patient goals, and associated trade-offs.[34,35] Time-limited trials may justify the short-term use of medical care that is overall considered discordant with a patient's presumed or previously stated goals. Such conversations ideally are initiated at an early stage of illness and revisited periodically.

Advance care planning, typically performed in advance of a serious illness, allows individuals to consider their

Stroke

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Table 1. Examples of Palliative Care Needs Checklists, Screening Tools, or Triggers That May Assist Health Care Professionals in the Timely Recognition and Management of Needs

Tool or trigger	Questions	Action suggestions
Surprise question[32] (adapted for stroke)	Would you be surprised if this patient: Dies within the next year? Dies during this hospitalization? Does not recover to independence?	If "no," consider a serious illness conversation (eg, advance care planning, family meeting, referral to palliative care team).
SuPPOrTT checklist[33]	Su: Does the patient or family need psychosocial or spiritual support or help with coping? P: Does the patient have pain or other distressing symptoms? PO: Does the patient or family have questions about prognosis or treatment options? rTT: Do we need to readdress goals of care or target treatment to patient-centered goals?	If "yes," consider a primary palliative care intervention (ie, a conversation with the patient and family focused on the identified needs), change in symptom management, or referral to the respective expert (eg, pain specialist, psychologist, chaplain, palliative care team) for specialist palliative care.
End of a time-limited trial[34,35]	A time-limited trial is a specified time frame in which to continue life-sustaining treatment to evaluate response and prognosis.	When this specified period has passed, another family meeting is key to assess symptoms and recovery, and to revisit goals of care.
Changes in living situation	Changes may include moving from a facility to home, increasing need for assistance with activities of daily living (eg, dressing, meals, toileting), and loss of ability to work or drive.	Any change can be stressful; a change in living situation may also signal a need for revisiting treatment options and goals of care. Referral to social work and support groups may be helpful.
Screening for caregiver distress or burnout	Ask care partners specifically about their role as a caregiver, their own wellbeing, and their ability to cope.	Acknowledge the care partner's role and possible strain, normalize feelings of overwhelm, and recognize burnout. Consider involving social work and peer support groups, and encourage caregivers to engage with their clinicians to address their own health care needs.
Screening for spiritual care needs (HOPE instrument)[36]	Explore sources of hope and inquire into organized religion, personal spiritual beliefs, and practices or restrictions that may affect medical care.	Consider referral to spiritual care or personal or community faith leader.

These tools are meant to help identify needs in a timely and routine manner and trigger certain actions depending on the respective need. This is not a comprehensive list; research in this area is ongoing.

Stroke

values and goals of medical care and to designate a surrogate to make decisions for them should they be unable to do so. After stroke, goals of care conversations should be considered alongside conversations about secondary stroke prevention[62–64]; however, although desired and recommended, these conversations are infrequent among stroke survivors.[63,65]

POSTACUTE CARE

Epidemiology

Stroke remains a leading cause of major disability and multimorbidity[66] requiring postacute care at home, in subacute care, such as rehabilitation settings, or in long-term care (eg, skilled nursing facilities). In a study from the National Hospital Care Survey of 36 519 patients hospitalized with stroke (International Classification of Diseases, 9th revision, codes 430–438) in 2014 in 94 US hospitals, 22.5% died either in the hospital or by the end of 2015; ≈6.8% died in the hospital and 15.7% died after discharge, with about half (8.6%) of deaths occurring >90 days after discharge.[67] There is wide variation in the categorization of reported discharge services and location for patients hospitalized with stroke. Two US-based studies that included patients with ischemic or hemorrhagic stroke reported that ≈34% to 45% were discharged home without additional services (eg, home

Table 2. Common Symptoms After Stroke

Symptoms	Management options	Considerations
Central poststroke pain	Antidepressants (tricyclics, selective serotonin reuptake inhibitors, serotonin-norepinephrine reuptake inhibitors)	Tricyclic antidepressants may lead to dry mouth or delirium
	Antiseizure medications	Most commonly lamotrigine, pregabalin, or gabapentin
Depression	Antidepressants	Agent selected on the basis of comorbidities and expected side effect profile
Hemiplegic shoulder pain	Physical therapy	Range of motion exercises
	Nonsteroidal anti-inflammatory agents	Can help improve range of motion before exercise
Spasticity	Stretching exercises	
	Muscle relaxants	
	Botulinum toxin	

This list focuses on common poststroke symptoms and is not comprehensive. Data derived from Greenway and Robinson.[40]

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health care, home hospice services); 10% to 11% were discharged home with home care or home health services; 30% to 42% were discharged to inpatient postacute care facilities, including inpatient rehabilitation facilities or skilled nursing facilities; 6% to 8% died in the hospital; 2% to 3% were discharged to an inpatient hospice facility; and 1% were discharged with home hospice.[21,67] Regardless of discharge destination, referrals to palliative care are typically low: in a review article of palliative care after stroke, it was reported that stroke comprises between 0.4% and 8.9% of referrals to specialist palliative care services, with most referrals being made near the end of life.[68]

Palliative Care for Stroke in the Postacute Setting

There is limited published research that focuses on postacute palliative care interventions after stroke. In a systematic review of quantitative studies from 1990 through 2021 describing poststroke palliative care interventions or end-of-life care, only 7 studies met review criteria; studies in this review reported on symptom burden, satisfaction with care, and needs of patients and families.[69] There were no randomized controlled trials evaluating poststroke palliative care interventions, and most studies focused on the final days of life. The authors concluded that there was limited evidence to guide how to integrate palliative care into routine stroke care, especially if prognosis was uncertain.[69]

Whereas not specific to palliative care, and focused on patients with stroke who were discharged from the hospital directly to home, a meta-analysis of 8 randomized controlled trials with 1196 stroke survivors from the United States (3 trials), Canada (4 trials), and Thailand (1 trial) found that receiving a case management intervention improved patients' mental health and activities of daily living.[70] The effects on care partners were not mentioned. A systematic review of 18 studies of family caregiver support and dyadic interventions after stroke suggests improved caregiver outcomes, including reduced burden and improved mental health and quality of life.[71] The authors highlight the need for more rigorous trials that focus on psychoeducational and skill-building interventions to improve caregiver outcomes. Several community-based palliative care models have been developed for heart failure and other serious noncancer illnesses that could also be adapted for stroke. Models are nurse-led, are designed to improve quality of life or symptom relief, and range in length from 3 to 12 months.[72–76] Adapting these models to stroke populations by integrating findings from the existing literature on the experiences of patients with stroke and their family care partners should be considered as a next step in addressing the postacute palliative care needs of patients with stroke. For stroke, interdisciplinary models that include specially trained nurses and social workers may be the most effective approach, given the multidimensional needs of patients with stroke and their family care partners.

Postacute Care of Family Members

There are limited randomized controlled trials focused on postacute stroke palliative care interventions for family members. A recent randomized pilot trial enrolled patient–care partner dyads from the neurologic intensive care unit (many patients, all of whom were able to communicate well, had experienced a stroke) into a 6-session longitudinal resiliency intervention designed to reduce long-term emotional distress in family members and patients. The pilot study demonstrated improved depression, anxiety, and posttraumatic stress in care partners at 12 weeks,[48] and additional studies of this intervention are ongoing. In addition, the AHA provides a comprehensive group of informational and support resources for patients with stroke and their family care partners to help them navigate life after stroke. Resources particularly relevant to palliative care[77] include information on caregiver support,[78] financial ramifications of stroke, recipe ideas for individuals with dysphagia, and links to local support groups.[79]

These and other resources are widely available on the Internet, but families need to be provided with guidance about which websites might be most helpful, given their individual situations and where they are in the stroke trajectory. They also need different types of resources at different times along the stroke trajectory,[30,80] which could be addressed by an interdisciplinary postacute stroke palliative care model that crosses the continuum of care from inpatient care to home.[81] These types of care models have been recommended and in some cases implemented for the stroke population in general,[81] but have not included a palliative care focus or a focus on patients and families faced with severe stroke leaving them with severe disability, disorders of consciousness, inability to participate in treatment decisions, or a combination of these.

END-OF-LIFE CARE AFTER STROKE

Most patients who die after stroke do so in the hospital or in nursing facilities[82] after a decision to withdraw or withhold life-sustaining therapy.[83,84] The proportion of patients with stroke who die at home is increasing.[82] Patients and families deserve comprehensive end-of-life symptom control, including intensive comfort measures and emotional support.[85] Patients who die of stroke often have altered consciousness or awareness, or difficulty communicating.[86] Health care professionals should perform regular pain assessments using both verbal (eg, 0–10 pain intensity scale) and nonverbal (eg, increased respiratory or heart rate, muscle tension, grimacing) indicators of discomfort. The most commonly documented symptoms after stroke at the end of life include pain

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(25%–65%) and dyspnea (16%–81%),[86] for which intermittent use of opioids and benzodiazepines is most effective, with escalating doses. In addition to managing restlessness and discomfort, clinicians also must counsel families on what to expect (eg, reduced food and fluid intake, decreased ability to cough, breathing noises and changes in breathing, reduced circulatory and renal function, reduced levels of consciousness, agitation). Respiratory secretions can increase as the ability to clear them decreases (ie, the death rattle), and is often more uncomfortable for family members than for the patient. The initial recommendation is to educate family members and reposition the patient; in addition, oral glycopyrrolate/scopolamine patches can reduce secretions.[87,88]

Hospice care is appropriate when the prognosis is ≤6 months and life-prolonging measures are not being pursued. Confusion and wide variability around hospice referrals exist, and there is no clear definition of what encompasses end-of-life care after stroke. For stroke, guidelines suggest that hospice could be considered when oral intake is limited and artificial nutrition is not pursued; complications of stroke occur, including aspiration pneumonia, sepsis, refractory sacral ulcers, or recurrent fevers; imaging findings indicate a poor prognosis; or coma has persisted for 3 days and is associated with the absence of a verbal response, brainstem reflexes, and withdrawal response to pain, along with poor renal function.[89] Guidelines to facilitate earlier consideration of hospice care for patients with known preferences that align with comfort care are needed.

Family members are the primary care partners for their loved one who is nearing the end of life. The hospice team includes nurses, physicians, social workers, spiritual advisors, aides, and often volunteers to provide support to patients and their family members. Hospice care can be provided in various locations. Inpatient hospice care or hospice at a facility is available when care is unable to be provided at home because of refractory symptoms or patients choose not to die in their home. In the United States, hospice services are covered under the Medicare benefit. Medicare does not pay for custodial care (eg, bathing, feeding, toileting), rehabilitation therapies, or room and board if a patient is receiving hospice care in a nursing home or a hospice inpatient facility.

CONCLUSIONS AND FUTURE DIRECTIONS

Since the previous AHA scientific statement on palliative care and stroke was published,[4] the palliative care approach has been established as an important part of high-quality stroke care not limited to patients who are dying. With the understanding that patients with stroke and their families experience an illness trajectory and needs that are distinct from those associated with other serious illnesses, researchers realize an urgent need to adapt existing models or create new ones that take into account the different challenges individuals face as they transition through the stroke care continuum. A key focus of research should be how to reliably deliver high-quality goal-concordant care for culturally diverse patients with stroke and their families and how to measure the success of this delivery. As noted in a recently published study[28] concerning cardiovascular disease in general, the concept of palliative pharmacotherapy specific to stroke requires further research.

Multidimensional needs assessment tools should be integrated into routine practice and education,[31] stroke specialist training should include goals of care communication training,[45] and specialist palliative care teams should be available for consultation when symptoms are refractory to first-line treatment, care partners are experiencing distress or burnout, or a goals-of-care or prognosis conversation requires more in-depth clinical training.

ARTICLE INFORMATION

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Julia Bu	Stroke Center, University of California San Diego	None	None	None	None	None	None	None
Amber Comer	Indiana University	None	None	None	None	None	None	None
Susan Enguidanos	University of Southern California Leonard Davis School of Gerontology	Administration for Community Living*	None	None	None	None	None	None
Barbara Lutz	University of North Carolina–Wilmington School of Nursing	NIH (serves as a coinvestigator on an NIH-funded grant studying the needs of patients with severe brain injury [eg, stroke] and their family members)†	None	MedBridge, Inc.*	None	None	None	UNCW (professor)†
Maisha T. Robinson	Mayo Clinic	None	None	None	None	None	None	None
Darin B. Zahuranec	University of Michigan	NIH (NINDS/NINR/NIA)†	None	None	None	None	None	None

This table represents the relationships of writing group members that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all members of the writing group are required to complete and submit. A relationship is considered to be "significant" if (a) the person receives $5000 or more during any 12-month period, or 5% or more of the person's gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns $5000 or more of the fair market value of the entity. A relationship is considered to be "modest" if it is less than "significant" under the preceding definition.

*Modest.

†Significant.

Stroke

Reviewer Disclosures

Reviewer	Employment	Research grant	Other research support	Speakers' bureau/ honoraria	Expert witness	Ownership interest	Consultant/ advisory board	Other
Tamilyn Bakas	University of Cincinnati	NIH/NINR (NIH funding targeting stroke family caregivers)†	None	None	None	None	None	None
Marco A. Gonzalez-Castellon	University of Nebraska	None	None	None	None	None	None	None
Mathew J. Reeves	Michigan State University	None	None	None	None	None	None	None
Ilana Ruff	Aurora Advocate Health	None	None	None	None	None	None	None
Alexis N. Simpkins	Cedars-Sinai Medical Center	None	None	None	None	None	None	None
Jessica Harman Thompson	University of Kentucky	None	NIH (K award, BIRCWH recipient, fellow, University of Kentucky)*	None	None	None	None	None

This table represents the relationships of reviewers that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all reviewers are required to complete and submit. A relationship is considered to be "significant" if (a) the person receives $5000 or more during any 12-month period, or 5% or more of the person's gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns $5000 or more of the fair market value of the entity. A relationship is considered to be "modest" if it is less than "significant" under the preceding definition.

*Modest.

†Significant.

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REFERENCES

1. Boersma I, Miyasaki J, Kutner J, Kluger B. Palliative care and neurology: time for a paradigm shift. *Neurology*. 2014;83:561–567. doi: 10.1212/WNL.0000000000000674
2. Creutzfeldt CJ, Wunsch H, Curtis JR, Hua M. Prevalence and outcomes of patients meeting palliative care consultation triggers in neurological intensive care units. *Neurocrit Care*. 2015;23:14–21. doi: 10.1007/s12028-015-0143-8
3. Quill TE, Abernethy AP. Generalist plus specialist palliative care: creating a more sustainable model. *N Engl J Med*. 2013;368:1173–1175. doi: 10.1056/NEJMp1215620
4. Holloway RG, Arnold RM, Creutzfeldt CJ, Lewis EF, Lutz BJ, McCann RM, Rabinstein AA, Saposnik G, Sheth KN, Zahuranec DB, et al; on behalf of the American Heart Association Stroke Council; Council on Cardiovascular and Stroke Nursing; and Council on Clinical Cardiology. Palliative and end-of-life care in stroke: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2014;45:1887–1916. doi: 10.1161/STR.0000000000000015
5. Kluger BM, Hudson P, Hanson LC, Bužgovà R, Creutzfeldt CJ, Gursahani R, Sumrall M, White C, Oliver DJ, Pantilat SZ, et al. Palliative care to support the needs of adults with neurological disease. *Lancet Neurol*. 2023;22:619–631. doi: 10.1016/S1474-4422(23)00129-1
6. Creutzfeldt CJ, Kluger B, Kelly AG, Lemmon M, Hwang DY, Galifianakis NB, Carver A, Katz M, Curtis JR, Holloway RG. Neuropalliative care: priorities to move the field forward. *Neurology*. 2018;91:217–226. doi: 10.1212/WNL.0000000000005916
7. Gunduz ME, Bucak B, Keser Z. Advances in stroke neurorehabilitation. *J Clin Med*. 2023;12:6734. doi: 10.3390/jcm12216734
8. Young MJ, Edlow BL, Bodien YG. Covert consciousness. *NeuroRehabilitation*. 2024;54:23–42. doi: 10.3233/NRE-230123
9. Morgenstern LB, Becker CJ, Lank R, Ortiz C, Zhang G, He K, Case E, Zahuranec DB. Long-term psychological distress among surrogate decision makers for Mexican American and non-Hispanic White patients with severe stroke. *Neurology*. 2024;102:e207960. doi: 10.1212/WNL.0000000000207960
10. Choo PY, Shaik MA, Tan-Ho G, Lee J, Ho AHY. Living losses in stroke caregiving: a qualitative systematic review of systematic reviews on psycho-socio-emotional challenges and coping mechanisms. *Int J Stroke*. 2023;18:268–277. doi: 10.1177/17474930221104908
11. Duncan PW, Bushnell C, Sissine M, Coleman S, Lutz BJ, Johnson AM, Radman M, Pvru Bettger J, Zorowitz RD, Stein J. Comprehensive stroke care and outcomes: time for a paradigm shift. *Stroke*. 2021;52:385–393. doi: 10.1161/STROKEAHA.120.029678
12. Borrell-Carrió F, Suchman AL, Epstein RM. The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *Ann Fam Med*. 2004;2:576–582. doi: 10.1370/afm.245
13. Towfighi A, Boden-Albala B, Cruz-Flores S, El Husseini N, Odonkor CA, Ovbiagele B, Sacco RL, Skolarus LE, Thrift AG; on behalf of the American Heart Association Stroke Council; Council on Cardiovascular and Stroke Nursing; Council on Cardiovascular Radiology and Intervention; Council on Clinical Cardiology; Council on Hypertension; Council on the Kidney in Cardiovascular Disease; and Council on Peripheral Vascular Disease. Strategies to reduce racial and ethnic inequities in stroke preparedness, care, recovery, and risk factor control: a scientific statement from the American Heart Association. *Stroke*. 2023;54:e371–e388. doi: 10.1161/STR.0000000000000437
14. Ikeme S, Kottenmeier E, Uzochukwu G, Brinjikji W. Evidence-based disparities in stroke care metrics and outcomes in the United States: a systematic review. *Stroke*. 2022;53:670–679. doi: 10.1161/STROKEAHA.121.036263
15. Portanova J, Ailshire J, Perez C, Rahman A, Enguidanos S. Ethnic differences in advance directive completion and care preferences: what has changed in a decade? *J Am Geriatr Soc*. 2017;65:1352–1357. doi: 10.1111/jgs.14800
16. Bailoor K, Shafie-Khorassani F, Lank RJ, Case E, Garcia NM, Lisabeth LD, Sanchez BN, Kim S, Morgenstern LB, Zahuranec DB. Time trends in race-ethnic differences in do-not-resuscitate orders after stroke. *Stroke*. 2019;50:1641–1647. doi: 10.1161/STROKEAHA.118.024460
17. Prabhakaran S, Cox M, Lytle B, Schulte PJ, Xian Y, Zahuranec D, Smith EE, Reeves M, Fonarow GC, Schwamm LH. Early transition to comfort measures only in acute stroke patients: analysis from the Get With The Guidelines–Stroke registry. *Neurol Clin Pract*. 2017;7:194–204. doi: 10.1212/cpj.0000000000000358
18. Kalasapudi L, Williamson S, Shipper AG, Motta M, Esenwa C, Otite FO, Chaturvedi S, Morris NA. Scoping review of racial, ethnic, and sex disparities in the diagnosis and management of hemorrhagic stroke. *Neurology*. 2023;101:e267–e276. doi: 10.1212/WNL.0000000000207406
19. Jones RC, Creutzfeldt CJ, Cox CE, Haines KL, Hough CL, Vavilala MS, Williamson T, Hernandez A, Raghunathan K, Bartz R, et al. Racial and ethnic differences in health care utilization following severe acute brain injury in the United States. *J Intensive Care Med*. 2021;36:1258–1263. doi: 10.1177/0885066620945911
20. Ahmed N, Krevat SA, Weintraub WS. Reducing racial/ethnic disparities in palliative care for stroke patients. *Cardiovasc Revasc Med*. 2022;35:155–156. doi: 10.1016/j.carrev.2021.11.031
21. Faigle R, Ziai WC, Urrutia VC, Cooper LA, Gottesman RF. Racial differences in palliative care use after stroke in majority-white, minority-serving, and racially integrated U.S. hospitals. *Crit Care Med*. 2017;45:2046–2054. doi: 10.1097/CCM.0000000000002762
22. Kelly AG, Zahuranec DB, Holloway RG, Morgenstern LB, Burke JF. Variation in do-not-resuscitate orders for patients with ischemic stroke: implications for national hospital comparisons. *Stroke*. 2014;45:822–827. doi: 10.1161/STROKEAHA.113.004573
23. Curtis JR, Lee RY, Brumback LC, Kross EK, Downey L, Torrence J, LeDuc N, Mallon Andrews K, Im J, Heywood J, et al. Intervention to promote communication about goals of care for hospitalized patients with serious illness: a randomized clinical trial. *JAMA*. 2023;329:2028–2037. doi: 10.1001/jama.2023.8812
24. Fischer SM, Min SJ, Kline DM, Lester K, Gozansky W, Schifeling C, Himberger J, Lopez J, Fink RM. Patient navigator intervention to improve palliative care outcomes for Hispanic patients with serious noncancer illness: a randomized clinical trial. *JAMA Intern Med*. 2024;184:384. doi: 10.1001/jamainternmed.2023.8145
25. Watts KA, Gazaway S, Malone E, Elk R, Tucker R, McCammon S, Goldhagen M, Graham J, Tassin V, Hauser J, et al. Community Telepal: a community-developed, culturally based palliative care tele-consult randomized controlled trial for African American and White rural southern elders with a life-limiting illness. *Trials*. 2020;21:672. doi: 10.1186/s13063-020-04567-w
26. Rattner M. 'Total pain': reverence and reconsideration. *Front Sociol*. 2023;8:1286208. doi: 10.3389/fsoc.2023.1286208
27. Givler A, Bhatt H, Maani-Fogelman PA. The importance of cultural competence in pain and palliative care. *StatPearls*; 2023. https://www.ncbi.nlm.nih.gov/books/NBK493154
28. Di Palo KE, Feder S, Baggenstos YT, Cornelio CK, Forman DE, Goyal P, Kwak MJ, McIlvennan CK; on behalf of the American Heart Association Clinical Pharmacology Committee of the Council on Clinical Cardiology and Council on Cardiovascular and Stroke Nursing. Palliative pharmacotherapy for cardiovascular disease: a scientific statement from the American Heart Association. *Circ Cardiovasc Qual Outcomes*. 2024;17:e000131. doi: 10.1161/HCQ.0000000000000131
29. Creutzfeldt CJ, Longstreth WT, Holloway RG. Predicting decline and survival in severe acute brain injury: the fourth trajectory. *BMJ*. 2015;351:h3904. doi: 10.1136/bmj.h3904
30. Cameron JI, Gignac MA. "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Educ Couns*. 2008;70:305–314. doi: 10.1016/j.pec.2007.10.020
31. Goni-Fuste B, Pergolizzi D, Monforte-Royo C, Alonso-Babarro A, Belar A, Crespo I, Güell E, Julià-Torras J, Moreno-Alonso D, Nabal Vicuña M, et al. Development of a guide to multidimensional needs assessment in the palliative care initial encounter (MAP). *J Pain Symptom Manage*. 2023;66:361–369.e6. doi: 10.1016/j.jpainsymman.2023.07.011
32. van Lummel EV, Ietswaard L, Zuithoff NP, Tjan DH, van Delden JJ. The utility of the surprise question: a useful tool for identifying patients nearing the last phase of life? A systematic review and meta-analysis. *Palliat Med*. 2022;36:1023–1046. doi: 10.1177/02692163221099116
33. Plinke WV, Buchbinder SA, Brumback LC, Longstreth WT, Kiker WA, Holloway RG, Engelberg RA, Curtis JR, Creutzfeldt CJ. Identification of palliative care needs and mental health outcomes among family members of patients with severe acute brain injury. *JAMA Netw Open*. 2023;6:e239949. doi: 10.1001/jamanetworkopen.2023.9949
34. Quill TE, Holloway R. Time-limited trials near the end of life. *JAMA*. 2011;306:1483–1484. doi: 10.1001/jama.2011.1413
35. Kruser JM, Ashana DC, Courtright KR, Kross EK, Neville TH, Rubin E, Schenker Y, Sullivan D, Thornton JD, Viglianti EM, et al. Defining

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the time-limited trial for patients with critical illness: an official American Thoracic Society workshop report. *Ann Am Thorac Soc*. 2024;21:187–199. doi: 10.1513/AnnalsATS.202310-925ST
36. Saguil A, Phelps K. The spiritual assessment. *Am Fam Physician*. 2012;86:546–550.
37. Ali M, Tibble H, Brady MC, Quinn TJ, Sunnerhagen KS, Venketasubramanian N, Shuaib A, Pandyan A, Mead G, on behalf of the VISTA Collaboration. Prevalence, trajectory, and predictors of poststroke pain: retrospective analysis of pooled clinical trial data set. *Stroke*. 2023;54:3107–3116. doi: 10.1161/STROKEAHA.123.043355
38. Gélinas C, Bérubé M, Puntillo KA, Boitor M, Richard-Lalonde M, Bernard F, Williams V, Joffe AM, Steiner C, Marsh R, et al. Validation of the Critical-Care Pain Observation Tool–Neuro in brain-injured adults in the intensive care unit: a prospective cohort study. *Crit Care*. 2021;25:142. doi: 10.1186/s13054-021-03561-1
39. Joffe AM, McNulty B, Boitor M, Marsh R, Gélinas C. Validation of the Critical-Care Pain Observation Tool in brain-injured critically ill adults. *J Crit Care*. 2016;36:76–80. doi: 10.1016/j.jcrc.2016.05.011
40. Greenway MRF, Robinson MT. Palliative care approaches to acute stroke in the hospital setting. *Handb Clin Neurol*. 2023;191:13–27. doi: 10.1016/B978-0-12-824535-4.00010-0
41. Kendall M, Cowey E, Mead G, Barber M, McAlpine C, Stott DJ, Boyd K, Murray SA. Outcomes, experiences and palliative care in major stroke: a multicentre, mixed-method, longitudinal study. *CMAJ*. 2018;190:E238–E246. doi: 10.1503/cmaj.170604
42. Meyerson D, Zuckerman D. *Identity Theft: Rediscovering Ourselves After Stroke*. Andrews McMeel Publishing; 2019.
43. Wendlandt B, Olm-Shipman C, Ceppe A, Hough CL, White DB, Cox CE, Carson SS. Surrogates of patients with severe acute brain injury experience persistent anxiety and depression over the 6 months after ICU admission. *J Pain Symptom Manage*. 2022;63:e633–e639. doi: 10.1016/j.jpainsymman.2022.02.336
44. Anderson S, Marlett NJ. Communication in stroke: the overlooked rehabilitation tool. *Age Ageing*. 2004;33:440–443. doi: 10.1093/ageing/afh163
45. Creutzfeldt CJ, Holloway RG, Curtis JR. Palliative care: a core competency for stroke neurologists. *Stroke*. 2015;46:2714–2719. doi: 10.1161/STROKEAHA.115.008224
46. Lyons KS, Lee CS. The theory of dyadic illness management. *J Fam Nurs*. 2018;24:8–28. doi: 10.1177/1074840717745669
47. Pucciarelli G, Lommi M, Magwood GS, Simeone S, Colaceci S, Vellone E, Alvaro R. Effectiveness of dyadic interventions to improve stroke patient-caregiver dyads' outcomes after discharge: a systematic review and meta-analysis study. *Eur J Cardiovasc Nurs*. 2021;20:14–33. doi: 10.1177/1474515120926069
48. Vranceanu AM, Bannon S, Mace R, Lester E, Meyers E, Gates M, Popok P, Lin A, Salgueiro D, Tehan T, et al. Feasibility and efficacy of a resiliency intervention for the prevention of chronic emotional distress among survivor-caregiver dyads admitted to the neuroscience intensive care unit: a randomized clinical trial. *JAMA Netw Open*. 2020;3:e2020807. doi: 10.1001/jamanetworkopen.2020.20807
49. Schutz RE, Coats HL, Engelberg RA, Curtis JR, Creutzfeldt CJ. Is there hope? Is she there? How families and clinicians experience severe acute brain injury. *J Palliat Med*. 2017;20:170–176. doi: 10.1089/jpm.2016.0286
50. Monod SM, Rochat E, Büla CJ, Jobin G, Martin E, Spencer B. The spiritual distress assessment tool: an instrument to assess spiritual distress in hospitalised elderly persons. *BMC Geriatr*. 2010;10:88. doi: 10.1186/1471-2318-10-88
51. Ernecoff NC, Curlin FA, Buddadhumaruk P, White DB. Health care professionals' responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions. *JAMA Intern Med*. 2015;175:1662–1669. doi: 10.1001/jamainternmed.2015.4124
52. Torke AM, Callahan CM, Sachs GA, Wocial LD, Helft PR, Monahan PO, Slaven JE, Montz K, Burke ES, Inger L. Communication quality predicts psychological well-being and satisfaction in family surrogates of hospitalized older adults: an observational study. *J Gen Intern Med*. 2018;33:298–304. doi: 10.1007/s11606-017-4222-8
53. Torke AM, Varner-Perez SE, Burke ES, Taylor TA, Slaven JE, Kozinski KL, Maiko SM, Pfeffer BJ, Banks SK. Effects of spiritual care on well-being of intensive care family surrogates: a clinical trial. *J Pain Symptom Manage*. 2023;65:296–307. doi: 10.1016/j.jpainsymman.2022.12.007
54. Oshvandi K, Torabi M, Khazaei M, Khazaei S, Yousofvand V. Impact of hope on stroke patients receiving a spiritual care program in Iran: a randomized controlled trial. *J Relig Health*. 2024;63:356–369. doi: 10.1007/s10943-022-01696-1
55. Halpern SD. Goal-concordant care: searching for the holy grail. *N Engl J Med*. 2019;381:1603–1606. doi: 10.1056/NEJMp1908153
56. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med*. 2014;174:1994–2003. doi: 10.1001/jamainternmed.2014.5271
57. Rutz Voumard R, Kiker WA, Dugger KM, Engelberg RA, Borasio GD, Curtis JR, Jox RJ, Creutzfeldt CJ. Adapting to a new normal after severe acute brain injury: an observational cohort using a sequential explanatory design. *Crit Care Med*. 2021;49:1322–1332. doi: 10.1097/CCM.0000000000004947
58. Creutzfeldt CJ, Holloway RG. Treatment decisions for a future self: ethical obligations to guide truly informed choices. *JAMA*. 2020;323:115–116. doi: 10.1001/jama.2019.19652
59. Jackson VA, Emanuel L. Navigating and communicating about serious illness and end of life. *N Engl J Med*. 2024;390:63–69. doi: 10.1056/NEJMcp2304436
60. Taylor LJ, Nabozny MJ, Steffens NM, Tucholka JL, Brasel KJ, Johnson SK, Zelenski A, Rathouz PJ, Zhao Q, Kwekkeboom KL, et al. A framework to improve surgeon communication in high-stakes surgical decisions: best case/worst case. *JAMA Surg*. 2017;152:531–538. doi: 10.1001/jamasurg.2016.5674
61. Kiker WA, Rutz Voumard R, Andrews LIB, Holloway RG, Brumback LC, Engelberg RA, Curtis JR, Creutzfeldt CJ. Assessment of discordance between physicians and family members regarding prognosis in patients with severe acute brain injury. *JAMA Netw Open*. 2021;4:e2128991. doi: 10.1001/jamanetworkopen.2021.28991
62. Miles NL, Abedini NC, Harris MH, Engelberg RA, Kross EK, Creutzfeldt CJ. Goals-of-care conversations after stroke survival. *Stroke*. 2024;55:e44–e45. doi: 10.1161/STROKEAHA.123.046119
63. Green T, Gandhi S, Kleissen T, Simon J, Raffin-Bouchal S, Ryckborst K. Advance care planning in stroke: influence of time on engagement in the process. *Patient Prefer Adherence*. 2014;8:119–126. doi: 10.2147/PPA.S54822
64. Skolarus LE, Brown DL, Reynolds E, Shi Y, Volow AM, Burke JF, Sudore RL. Advance care planning engagement may increase among stroke survivors: results from the PREPARE for your care trial. *Stroke*. 2022;53:e477–e478. doi: 10.1161/STROKEAHA.122.040386
65. Johnson PD, Ulrich A, Siv J, Taylor B, Tirschwell D, Creutzfeldt CJ. Planning after stroke survival: advance care planning in the stroke clinic. *J Am Heart Assoc*. 2019;8:e011317. doi: 10.1161/JAHA.118.011317
66. Tsao CW, Aday AW, Almarzooq ZI, Anderson CAM, Arora P, Avery CL, Baker-Smith CM, Beaton AZ, Boehme AK, Buxton AE, et al; on behalf of the American Heart Association Council on Epidemiology and Prevention Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics: 2023 update: a report from the American Heart Association. *Circulation*. 2023;147:e93–e621. doi: 10.1161/CIR.0000000000001123
67. Jackson G, Chari K. National Hospital Care Survey demonstration projects: stroke inpatient hospitalizations. *Natl Health Stat Report*. 2019;32:1–11.
68. Cowey E, Schichtel M, Cheyne JD, Tweedie L, Lehman R, Melifonwu R, Mead GE. Palliative care after stroke: a review. *Int J Stroke*. 2021;16:632–639. doi: 10.1177/17474930211016603
69. Govind N, Ferguson C, Phillips JL, Hickman L. Palliative care interventions and end-of-life care as reported by patients' post-stroke and their families: a systematic review. *Eur J Cardiovasc Nurs*. 2023;22:445–453. doi: 10.1093/eurjcn/zvac112
70. Saragih ID, Saragih IS, Tarihoran D, Sharma S, Chou FH. A meta-analysis of studies of the effects of case management intervention for stroke survivors across three countries. *J Nurs Scholarsh*. 2023;55:345–355. doi: 10.1111/jnu.12822
71. Bakas T, McCarthy MJ, Miller EL. Systematic review of the evidence for stroke family caregiver and dyad interventions. *Stroke*. 2022;53:2093–2102. doi: 10.1161/STROKEAHA.121.034090
72. Kavalieratos D, Harinstein ME, Rose B, Lowers J, Hoydich ZP, Bekelman DB, Allen LA, Rollman BL, Ernecoff NC, Moreines LT, et al. Primary palliative care for heart failure provided within ambulatory cardiology: a randomized pilot trial. *Heart Lung*. 2022;56:125–132. doi: 10.1016/j.hrtlng.2022.07.002
73. Bakitas MA, Dionne-Odom JN, Ejem DB, Wells R, Azuero A, Stockdill ML, Keebler K, Sockwell E, Tims S, Engler S, et al. Effect of an early palliative care telehealth intervention vs usual care on patients with heart failure: the ENABLE CHF-PC randomized clinical trial. *JAMA Intern Med*. 2020;180:1203–1213. doi: 10.1001/jamainternmed.2020.2861
74. Graney BA, Au DH, Baron AE, Cheng A, Combs SA, Glorioso TJ, Paden G, Parsons EC, Rabin BA, Ritzwoller DP, et al. Advancing Symptom Alleviation with Palliative Treatment (ADAPT) trial to improve quality of

Stroke
American Stroke Association.
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life: a study protocol for a randomized clinical trial. *Trials*. 2019;20:355. doi: 10.1186/s13063-019-3417-1
75. Rogers JG, Patel CB, Mentz RJ, Granger BB, Steinhauser KE, Fiuzat M, Adams PA, Speck A, Johnson KS, Krishnamoorthy A, et al. Palliative care in heart failure: the PAL-HF randomized, controlled clinical trial. *J Am Coll Cardiol*. 2017;70:331–341. doi: 10.1016/j.jacc.2017.05.030
76. Bekelman D, Feser W, Baron A, Parsons EC, Welsh CH, Paden G, McBryde C, Cheng C, Turvey C, Au DH. Effect of a collaborative palliative care intervention vs usual care on quality of life of patients with symptomatic heart and lung diseases: the ADAPT randomized clinical trial. *Am J Respir Crit Care Med*. 2022;205:A2369. 10.1164/ajrccm-conference.2022.205.1_MeetingAbstracts.A2369
77. American Heart Association. Palliative Care. Accessed June 6, 2024. https://www.stroke.org/en/life-after-stroke/recovery/managing-your-stroke/palliative-care
78. American Heart Association. Family Caregivers. Accessed June 6, 2024. https://www.stroke.org/en/help-and-support/for-family-caregivers
79. American Heart Association. Help and Support. Accessed June 6, 2024. https://www.stroke.org/en/help-and-support
80. Cameron JI, Naglie G, Gignac MAM, Bayley M, Warner G, Green T, Czerwonka A, Huijbregts M, Silver FL, Phillips SJ, et al. Randomized clinical trial of the Timing it Right Stroke Family Support Program: research protocol. *BMC Health Serv Res*. 2014;14:18. doi: 10.1186/1472-6963-14-18
81. Camicia M, Lutz B, Summers D, Klassman L, Vaughn S. Nursing's role in successful stroke care transitions across the continuum: from acute care into the community. *Stroke*. 2021;52:e794–e805. doi: 10.1161/STROKEAHA.121.033938
82. Cross SH, Kaufman BG, Warraich HJ. Trends in location of death for individuals with cerebrovascular disease in the United States. *JAMA Neurol*. 2019;76:1399–1401. doi: 10.1001/jamaneurol.2019.2566
83. Alonso A, Ebert AD, Dörr D, Buchheidt D, Hennerici MG, Szabo K. End-of-life decisions in acute stroke patients: an observational cohort study. *BMC Palliat Care*. 2016;15:38. doi: 10.1186/s12904-016-0113-8
84. Kelly AG, Hoskins KD, Holloway RG. Early stroke mortality, patient preferences, and the withdrawal of care bias. *Neurology*. 2012;79:941–944. doi: 10.1212/WNL.0b013e318266fc40
85. Blinderman CD, Billings JA. Comfort care for patients dying in the hospital. *N Engl J Med*. 2015;373:2549–2561. doi: 10.1056/NEJMra1411746
86. Ramsburg H, Moriarty HJ, MacKenzie Greenle M. End-of-life symptoms in adult patients with stroke in the last two years of life: an integrative review. *Am J Hosp Palliat Care*. 2024;41:831–839. doi: 10.1177/10499091231197657
87. Ferris FD, von Gunten CF, Emanuel LL. Competency in end-of-life care: last hours of life. *J Palliat Med*. 2003;6:605–613. doi: 10.1089/109662103768253713
88. Moons L, De Roo ML, Deschodt M, Oldenburger E. Death rattle: current experiences and non-pharmacological management: a narrative review. *Ann Palliat Med*. 2024;13:150–161. doi: 10.21037/apm-23-507
89. Centers for Medicare & Medicaid Services. Hospice Determining Terminal Status. Accessed April 1, 2024. https://www.cms.gov/medicare-coverage-database/view/lcd.aspx?LCDId=34538

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